



Allergic Diseases SIG

Spring/Summer Newsletter 2024

Supporting Caregivers across Allergic Diseases

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A Message from our Co-Chairs

Welcome to our latest newsletter from the Allergic Disease SIG. We have several updates to provide, and we are grateful for your interest and continued work for pediatric allergic diseases. The leadership team at the Allergic Disease SIG has a number of exciting new projects and initiatives that we hope will support the diverse and exciting work that psychologists in this area are doing!

We would like to start by thanking our outgoing board members and briefly introducing our new leadership team.

Thank you to: Dr. Mallory Netz (Co-Chair), Dr. Alayna Tackett (Research Chair), Dr. Rachel Tenenbaum (Clinical Chair), Dr. Melissa Engel (Social Media Chair), and Natalie Koskela-Staples (Student Representative)! We appreciate your efforts and engagement in supporting our SIG.

≡ Welcome ≡



Dr. Haley Killian (Co-Chair): Dr. Killian is a Clinical Assistant Professor in the Department of Pediatrics at UMKC School of Medicine and Pediatric Psychologist at Children's Mercy Kansas City. She provides clinical care to patients within several subspecialty medical clinics, one of which is the Dermatology Clinic. Through this clinic, I provide support to children and adolescents with atopic dermatitis and other skin related diseases.



Dr. Jennifer LeBovidge (Clinical Chair): Dr. LeBovidge is a pediatric psychologist in the Division of Allergy and Immunology at Boston Children's Hospital and an Assistant Professor of Psychology at Harvard Medical School. She provides care for children with allergic diseases and their families within the Food Allergy Program, Food Protein-Induced Enterocolitis Syndrome (FPIES) Program, and Atopic Dermatitis (AD) Center at Boston Children's. She also supervises psychology interns in the multidisciplinary AD Center. Her recent research has focused on enhancing patient and family self-efficacy in managing allergic diseases at different developmental stages. She has previously served as the Co-chair of the Allergic Diseases SIG and is excited take on the role of Clinical Chair.



Dr. Grace Cushman (Research Chair): Dr. Cushman is currently a postdoctoral fellow and will be transitioning to a research scientist position at Brown/Hasbro Children's Hospital this summer. Her current research focuses on understanding barriers and facilitators to food allergy prevention and management efforts. Broadly, she is interested in identifying individual, family, and system-level factors that may impact allergic disease management and shared decision making with families. Clinically, Dr. Cushman focuses on supporting pediatric patients and their families with allergic disease care and psychosocial adjustment throughout developmental stages and life transitions.



Sabrina Sigel (Student Trainee Representative): Sabrina graduated from the George Washington University in 2023 and joined the Division of Allergy and Immunology at Children's National Hospital in June 2023. She is the Clinical Research Coordinator for Dr. Linda Herbert's Food Allergy Mastery Program R01 study. Her focus is on adolescents with food allergy and their psychosocial functioning and management.

The aim of the current issue is to provide resources and commentary on supporting caregivers across allergic conditions. Dr. Voorhees has coordinated these efforts among our leadership team, and she starts us out with a recap of SPPAC and SIGs on Parade.

In an effort to continue our work and mission to enhance and improve support to children with allergic diseases, Dr. LeBovidge has organized an expert interview with Korey Capozza from Global Parents for Eczema Research to help inform our practice.

Dr. Cushman and our student trainee representatives (Frances Cooke and Sabrina Sigel) reviewed a recent research article on supporting caregivers of children with food allergies. It is our hope that this can provide a recap on the current state of research in this area and provide tips to enhance our work with the patients and families we provide care to within our SIG.

We hope that the content of our current newsletter may help to frame and guide both clinical and research efforts going forward and we hope that you gain some knowledge or helpful resources to support your work.

We are looking forward to continuing to support our SIG members in various domains of their careers. If there are other things that we could do to support you in your work, please do not hesitate to reach out to us. You can contact either of the co-chairs via email (kaitlin.proctor@choa.org and hjkillian@cmh.edu) with information you would like to share with our membership or if you are interested in supporting any of our SIG initiatives.

Best, Kaitlin Proctor, PhD, ABPP and Haley Killian, PhD

Leadership Committee

Name	Role
Kaitlin Proctor, PhD, ABPP	<i>Co-Chair</i>
Haley Killian, PhD	<i>Co-Chair</i>
Jennifer LeBovidge, PhD	<i>Clinical Chair</i>
Sara Voorhees, PhD	<i>Communications Chair</i>
Grace Cushman, PhD	<i>Research Chair</i>
Frances Cooke	<i>Student Representative</i>
Sabrina Sigel	<i>Student Representative</i>

Contact the SIG: allergicdiseasesSIG@gmail.com

SPPAC and SIGs on Parade Recap

We hope everyone had as much fun in New Orleans as we did! We have been feeling energized and motivated following all of the incredible presentations throughout the conference (in addition to being well-fueled by the amazing food in NOLA!). It was exciting to see our SIG members who gave incredible presentations and we are especially proud of our student members who presented posters during the Thursday evening poster session.



One of our favorite moments of the SPPAC weekend was SIGs on parade! We loved seeing SIG members and meeting many new faces. Shoutout to our student reps who planned an awesome activity for those stopping by our table - we had a matching game (match the photos of various nuts with the correct name of the nut) that was a huge hit!

We look forward to networking opportunities at future SPP/SIG events and conferences.

Ask the Expert: Q&A with Korey Capozza, MPH from Global Parents for Eczema Research



Korey Capozza, MPH is a mother of a child with moderate to severe eczema and the founder of Global Parents for Eczema Research (GPER), an international coalition of parents of children with moderate to severe eczema focused on advancing patient-centered research.

Korey recently spoke with Dr. Jenny LeBovidge, the Allergic Diseases SIG Clinical Chair, about the experiences and support needs of caregivers of children with eczema (atopic dermatitis).

Q: What are some of the biggest challenges for parents or other caregivers of children with eczema?

A: “I think caregivers of children with mild eczema are doing OK, for the most part; it's the caregivers of children with moderate to severe eczema who are struggling. They experience difficulties in finding a provider who understands the complexity of the condition, challenges with accessing effective and safe treatments, social isolation, guilt, and exhaustion. We find that parents, especially moms, feel judged because their child is so visibly affected by eczema, and often when the condition is out of control, it's very hard to manage.”

Q: What has your experience been like as a parent of a child with eczema?

A: “Well, before we found an effective treatment for my son, it was non-stop misery for him and for us. One of the hardest things is watching your child suffer without a way to help. On top of that, I remember feeling abject exhaustion because like many parents, I would stay up all night to keep my son from scratching and crying at night. The next day you are destroyed with fatigue, but you carry on with work and childcare because you have to. It can be crushing. However, we did find an effective treatment for my son and it changed his life. I almost don't remember those days now because he, and we, have been able to lead normal lives with eczema mostly a non-issue for us now.”

Q: What led you to found GPER?

A: “My professional background was in community-based research and patient/consumer engagement prior to starting GPER. Through work, I saw a grant opportunity from the new Patient Centered Outcomes Research Institute to improve the participation of patients and caregivers in research. At that time, I was struggling with the lack of research and evidence to support treatment decisions for my son and the conflicting advice we would receive from providers. There hadn't been a significant new treatment for pediatric eczema in decades. I thought: we need more urgency around solutions for these kids. It felt like the condition wasn't taken seriously, yet my own experience was just the opposite: it was devastating to our quality of life. I connected with another dad who was going through the same thing, and we applied for the grant with the hope of starting an organization that would advocate for the research that parents wanted to see done. We were successful, and GPER was born in 2015, with strong support from the global parent community. We have always been grassroots and participatory in structure which has enabled us to stay close to the unmet needs in the community.”

Q: Can you tell us a little bit about your parent-to-parent support program?

A: “Sure, this peer support program was borne out of our survey research on caregiver burden, which we published in 2020. Our findings pointed to incredible distress among eczema caregivers (again the ones dealing with moderate to severe disease). We saw very high rates of self-reported anxiety, depression, isolation and exhaustion. We knew this was a problem because many of us staffers at GPER had lived it, but to see the experience of so many others in the data was eye opening. This was also during the beginning of the COVID-19 epidemic, so it was a challenging time for all of us. As an organization we wondered how we could address this need among caregivers and decided to develop a peer support program because there was compelling evidence from other chronic conditions that it could help and because we were well positioned to take that on as a caregiver-led organization.”

Q: Are there key take-aways from the research you have conducted with caregivers of children with eczema?

A: “Yes! First and foremost, to help children with serious eczema, we need to start with making sure the caregivers are OK. They are the ones managing the eczema day to day, and if they are exhausted, stressed, anxious or depressed, they can't do that critical job. Second, caregivers need someone to talk to and relate to in their struggles, and that person is usually not a healthcare provider. Patient organizations like ours can play a critical role in reducing isolation and empowering parents. It's very healing to talk to another person who "gets it". Finally, we must direct our energy towards getting eczema under control in early childhood so that these children can go on to have normal lives. Early, effective intervention can stop the atopic march, and restore the quality of life of families.”

Q: What do you think are some of the most important things for mental health professionals to know about eczema?

A: “That it has a profound mental health impact that's not visible. That the itch torments children and their parents, and getting that under control is essential. That addressing the mental health of the parent is step 1 to better health for these children.”

References on caregiver burden of eczema/atopic dermatitis:

1) Capozza K, Gadd H, Kelley K, Russell S, Shi V, Schwartz A. Insights From Caregivers on the Impact of Pediatric Atopic Dermatitis on Families: "I'm Tired, Overwhelmed, and Feel Like I'm Failing as a Mother". *Dermatitis : contact, atopic, occupational, drug*. Feb 21 2020;doi:10.1097/der.0000000000000582

2) Kim RW, Barta K, Begolka WS, et al. Qualitative analysis of the impact of atopic dermatitis on caregivers. *The British journal of dermatology*. Aug 16 2022;doi:10.1111/bjd.21828

Mentored Article Review

Written by: Frances Cooke and Sabrina Sigel

Mentored by: Grace Cushman, PhD

Article:

Golding, M. A., Simons, E., Abrams, E. M., Gerdtts, J., & Protudjer, J. L. P. (2021). The excess costs of childhood food allergy on Canadian families: a cross-sectional study. *Allergy, asthma, and clinical immunology : official journal of the Canadian Society of Allergy and Clinical Immunology*, 17(1), 28. <https://doi.org/10.1186/s13223-021-00530-9>

The financial burden of food allergy on families was examined in “The excess of costs of childhood food allergy on Canadian families: A cross-sectional study,” by Golding and colleagues. The purpose of the study was to examine direct, indirect, and intangible annual costs among Canadian families with and without a child with food allergy.

Thirty five families with a child with food allergy and 35 families with no child with food allergy were recruited and matched based on demographic characteristics. Parents completed the Food Allergy Economic Questionnaire (FA-EcoQ) to assess their food-allergy related costs. Direct costs are paid for by the household and consist of travel to medical care, food, and treatments. Indirect costs include loss of time and wages. Intangible costs are ones that cannot be measured by dollar amounts (e.g., family well-being, satisfaction with their income). Variables such as household income and the number of people living in the home were controlled for in the statistical analysis.

Results indicate that families with a child with food allergy experience higher direct costs (~20% higher) compared to families who do not have a child with food allergy. The researchers discovered that this was due partially to the cost of food. Notably, these differences in direct costs were present for families above the median income, whereas differences in indirect costs were mostly present for families below the median income level. Intangible costs were also higher for children with food allergy, but not other family members. Additionally, families with a child with food allergy reported their child having a lower quality of life than the families with a child without food allergy.

This research expands on extant literature on the economic burden of food allergy that had previously focused on families in Sweden and the United States. By studying Canadian families for the first time, Golding and colleagues have helped obtain a more nuanced understanding of the financial barriers and facilitators of food allergy management in countries with varying cost of living and healthcare systems.

The findings of this research offer some notable takeaways. First, based on the results, it appears that there is not one singular aspect of food allergy management that increases financial burden for families with a child with food allergy compared to families without a child with food allergy. Rather,

the direct financial burden of managing food allergy stems from a combination of affording safe foods and medication, and covering the cost of medical appointments. Second, the results emphasize the importance of considering indirect costs. Until a child is old enough to manage their food allergy independently, caregivers are the primary manager responsible for preparing safe foods, researching information on food allergy management, and organizing the attendance of medical appointments. Even small increments of time dedicated to these tasks can add up to incur significant loss of wages or time for caregivers. The research findings suggest that families managing a food allergy with lower income may be even more greatly impacted by these indirect costs than families with higher income. While the researchers did not find differences in perceived quality of life of caregivers, these findings suggest that the tasks that are medically necessary for managing food allergy can be financially burdensome for caregivers.

This study has implications for future research and clinical practice. Golding and colleagues note the importance of conducting similar research in countries with different economic and healthcare landscapes. Researchers may consider replicating this research in other countries, with a focus on collecting a sample that is representative of the socioeconomic breakdown of the population. Pediatric psychologists working in clinical settings can apply these research findings to their work with caregivers of children with food allergy by making information and resources on food allergy management more accessible to caregivers, especially any resources on financial support. Psychologists can also assess the financial impact of food allergy management on families' daily lives. These conversations should be implemented in sensitive and systematic ways, encapsulating both direct and indirect cost, without assuming who may or may not need support. Lastly, mental health professionals working with families with food allergy can use their expertise to advocate for programs and policies that create direct financial support for families experiencing significant burden.

Food allergy management is required for the wellbeing and safety of children. Researchers and clinicians can help support caregivers and their families by focusing on the financial impact of these daily tasks and working to reduce the demonstrated burden.

Recent Articles on Parent/Caregiver Coping in Allergic Diseases

Systematic Reviews

- 1) Knibb, R. C., Jones, C. J., Herbert, L. J., & Screti, C. (2024). Psychological support needs for children with food allergy and their families: A systematic review. *Pediatric Allergy and Immunology*, 35(3), e14108.
- 2) Klinnert, M. D., Booster, G., Copeland, M., Darr, J. M., Meltzer, L. J., Miller, M., ... & Bender, B. G. (2018). Role of behavioral health in management of pediatric atopic dermatitis. *Annals of Allergy*,

Observational Studies

- 3) Chooniedass, R., Soller, L., Hsu, E., To, S., Cameron, S. B., & Chan, E. S. (2020). Parents of children with food allergy: a qualitative study describing needs and identifying solutions. *Annals of Allergy, Asthma & Immunology*, 125(6), 674-679.
- 4) Bozen, A., Kanaley, M. K., Negriz, O., Gupta, R. S., & Lombard, L. (2020). Pediatric allergists' perspectives on the psychosocial challenges of food allergy and factors that support coping. *Annals of Allergy, Asthma & Immunology*, 124(5), 515-516.
- 5) Rodríguez, E. M., Gulbas, L. E., Horner, S. D., Alba-Suarez, J., George-Jones, J., Davidson, S., ... & Alvarado, C. (2020). Stress and coping in pediatric asthma: The experiences of low-SES Latinx families. *Clinical Practice in Pediatric Psychology*, 8(2), 126.
- 6) Tully, C., Rose, M., Breen, S., Herrera, N., Shelef, D. Q., Streisand, R., & Teach, S. J. (2019). Relationship between parent mood and resilience and child health outcomes in pediatric asthma. *Families, Systems, & Health*, 37(2), 167.

Intervention Studies

- 7) Boyle, R. J., Umasunthar, T., Smith, J. G., Hanna, H., Procktor, A., Phillips, K., ... & Hodes, M. (2017). A brief psychological intervention for mothers of children with food allergy can change risk perception and reduce anxiety: outcomes of a randomized controlled trial. *Clinical & Experimental Allergy*, 47(10), 1309-1317.
- 8) Rodríguez, E. M., Horner, S. D., Bearman, S. K., Gulbas, L., George-Jones, J., Alvarado, C., & Esperanza, C. (2022). Development and pilot randomized trial of a coping skills intervention for low-SES Latinx families of children with asthma. *Clinical practice in pediatric psychology*, 10(2), 115.

